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Testimony of Deborah Morosini, M.D. Social Security Administration Compassionate Allowance Outreach Hearing on Cancers Monday, April 7, 2008

I am Deborah Morosini, a medical doctor and a member of the Board of Directors of Lung Cancer Alliance, the only national non profit organization dedicated exclusively to patient support and advocacy for those living with or at risk for lung cancer. We deeply appreciate the opportunity to testify before this distinguished panel.

I understand that this is the second Compassionate Allowance Outreach hearing that you have held to consider ways to expedite the processing and delivery of disability benefits to patients whose medical conditions that meet the definition of disability under the Social Security Act.

We would like to thank Commissioner Astrue for his leadership and compassion concern about this issue and for the invitation to present testimony. We would like to acknowledge also the assistance of the Office of the Director of the National Cancer Institute for recommending our participation.

By initiating these hearings, Commissioner Astrue has sent a message of hope to patients with serious illnesses who face enormous financial challenges in addition to the physical and emotional demands of dealing with their disease. Easing some of that burden would be of great benefit to these patients and to their families, many of whom are stretched beyond the limit. We commend you for addressing this and urge that the definition of conditions qualifying for expedited consideration under Compassionate Allowances include late stage lung cancer.

The public health impact of lung cancer is devastating. It is the leading cancer killer in the United States, taking more lives each year than breast, prostate and colon cancers combined. Lung cancer will take the live of nearly twice as many women as breast cancer and over three times as many men as prostate cancer. While the five year survival rates for breast, prostate, and colon cancers have risen to 88%, 99% and 65% respectively, lung cancer's five year survival rate is still at only 15%.

For late stage lung cancer the statistics are even grimmer. Of the estimated 214,000 new cases of lung cancer that will be diagnosed this year, 140,000 will be Stage IIIb or Stage IV. By the time symptoms appear, lung cancer has usually advanced to late stage, and the five year survival rate if less than 5%. Most lung cancer patients die within a year of diagnosis, as I know all too well.

According to statistics from Surveillance, Epidemiology and End Results (SEER) at the National Cancer Institute (NCI), the median survival time for Stage IIIb non small cell lung cancer is 12 months and Stage IV is eight months. The median survival time for Stage IV small cell lung cancer is six months.

Thus, the current 45 day application period and five to six month processing time for disability benefits constitute a *de facto* denial of benefits to a large number of these patients.

The burden on these patients is enormous. LCA is the only lung cancer specific national organization providing patient support services. We receive hundreds of calls and emails every week from patients

trying desperately to cope not only with the physical and emotional burden of this disease, but also with the significant financial problems of treatment.

On January 3, 2007, the Journal of the National Cancer Institute (JNCI) published the results of a study on patient time costs associated with cancer care. The highest patient time costs were associated with lung cancer and accounted for over a third of the patient time costs for all eleven cancers reviewed for the study.

These cost burdens fall particularly hard on veterans and African American males who are at a disproportionately 25% higher risk for lung cancer incidence and mortality.

As the sister of wonderful woman struck down by lung cancer in the prime of her life, I am dedicated to helping to change public health policy so that lung cancer research is no longer the least funded of all the major cancers and that lung cancer patients are no longer stigmatized and blamed for their disease. And, sadly, this has been the case even though over 50% of lung cancer patients are former smokers and another 10 to 15% non smokers. One in five women being diagnosed now with lung cancer have never smoked

Like the majority of lung cancer patients, my beautiful sister, Dana Reeve, was diagnosed with late stage lung cancer and died seven months later. Sadly, Dana's case is the norm rather than the exception with lung cancer. I urge you, and I know that she would urge you, to include late stage lung cancer in your Compassionate Allowances Initiative.

I have attached the pertinent charts and studies referred to my testimony. Thank you very much for the opportunity to testify.

Attachments